

# An Online Communication Tool Alters the Way Patients Find Information

Stephanie Prady<sup>1</sup>, Yolanda Finegan<sup>1</sup>, John Lester<sup>1,2</sup>, Lisa Daly, R.N., M.S.<sup>1</sup>, Daniel B. Hoch Ph.D., M.D.<sup>1,2</sup>

<sup>1</sup> Massachusetts General Hospital, Boston

<sup>2</sup> Harvard Medical School, Boston

**Abstract.** Epilepsy Patients and users of an online educational and communication resource were polled about their information needs over time. Subjects appear to prefer to communicate with their specialist digitally rather than talk on the telephone or have a face-to-face visit. The longer the patients have access to the resource, the less likely they are to plan to make a face-to-face doctors office visit for information needs.

**Introduction:** PatientWeb is a healthcare communication tool currently being studied by the Epilepsy Service at Massachusetts General Hospital. Patients can use the system to communicate privately and securely with their care providers, interact anonymously with other patients if they wish, and browse a library of information and links relating to epilepsy. One of the outcome measures for study participants is an online survey administered at three-monthly intervals. The survey assesses information needs and retrieval methods used by the patients over the preceding three months.

**Participants, Methods and Results:** Subjects are patients of the MGH Neurology (Epilepsy) Service or in rare instances, the caregivers of those with epilepsy, who have enrolled in the PatientWeb project. A survey of need for information and plans to gain the information was presented as a hypertext link in the patient's private folder area by the PI. The link and a request to fill out the questionnaire was presented to each of the 72 subjects, starting 3 months from the date of enrollment and thereafter at 3 monthly intervals.

The response rate for the surveys was low. Of 38 subjects who had been enrolled for at least 6 months, 42% completed any two consecutive surveys and were included in this analysis. Seventy-one percent from the first survey and 88% from the second had sought information about Epilepsy over the preceding three months. The most popular method for finding information was by contacting their epilepsy specialist via PatientWeb (74%). The other methods

were to go to a medical website (48%), use the PatientWeb bulletin board to anonymously contact other patients (27%) or lastly, get information from another online self-help site (15%). Patients were significantly more likely to contact their provider via PatientWeb than via an office visit or telephone call combined, and more patients contacted other patients than visited their doctor face to face.

When asked about their current need for information about Epilepsy and how they planned to get answers to their questions, users overwhelmingly responded that they would contact their epilepsy specialist via PatientWeb. When comparing responses over time, there was a trend for patients to favor going to a website rather than using books or pamphlets. A significant decrease in the number of patients planning to visit their healthcare provider was noted in the three months between surveys. (71% at first survey, none in the second survey).

**Comment:** Patients using an online resource comprised of both health education content and interpersonal communication tools to coordinate their Epilepsy care are significantly more likely to communicate their non-urgent needs to their health care provider online than contact them via telephone or request a face-to-face appointment. Further, patient's plans for obtaining information are influenced by having access to a communication tool such as PatientWeb. They plan to make fewer office visits to their health care providers and use other tools to answer their questions. Although the findings are in keeping with others who have studied the use of online resources, our observations are limited by a low response rate and small numbers. Nevertheless, the findings lead to interesting speculation about the future of face to face medical care given the growing electronic expertise and empowerment of the average consumer.